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# Lived experiences of end-of-life communication among nursing home staff An interpretive phenomenological study

Silvia Gonella, Alessio Conti, Beatrice Albanesi, Alexandra Antal, Valerio Dimonte, Paola Di Giulio

### Affiliations

Silvia Gonella Department of Public Health and Pediatrics, University of Torino, Torino, Italy

Silvia Gonella Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino, Torino, Italy

Alessio Conti Department of Public Health and Pediatrics, University of Torino, Torino, Italy

Beatrice Albanesi Department of Public Health and Pediatrics, University of Torino, Torino, Italy

Alexandra Antal Department of Public Health and Pediatrics, University of Torino, Torino, Italy

Valerio Dimonte Department of Public Health and Pediatrics, University of Torino, Torino, Italy

Valerio Dimonte Azienda Ospedaliero Universitaria Città della Salute e della Scienza di Torino, Torino, Italy

Paola Di Giulio Department of Public Health and Pediatrics, University of Torino, Torino, Italy

## Correspondence

Beatrice Albanesi Department of Public Health and Pediatrics, University of Torino, Via Santena 5 bis, 10126 Torino, Italy. Email: beatrice.albanesi@unito.it

## Abstract

Aims: To explore and understand lived experiences of end-of-life communication among nursing home staff.

Design: Interpretive phenomenological study.

Methods: In-person, semi-structured, in-depth interviews were conducted from May to August 2021 with 21 nursing home staff members involved in end-of-life communication (four managers, four chief nurses, three chief medical officers, three nurses, three psychologists, two occupational therapists, one chief nurse aide and one nurse aide). Data were analysed by van Manen's hermeneutic approach, which uses the lifeworld existentials of spatiality, corporeality, temporality and relationality to guide reflection on the human experience. Data were reported according to the Consolidated Criteria for Reporting Qualitative Research.

Results: Thirteen categories were identified and framed within the four existentials. Regarding spatiality, end-of-life communication took place in a physical, mental, socio-cultural and professional competence space. With regard to corporeality, interviewees reported difficulties in managing their own feelings and those of family caregivers. For temporality, interviewees reported delays in end-of-life communication due to staffing issues and an increase in urgent and temporary relief admissions to nursing homes. To

compensate, they tried to assure that all interactions that did take place were of high quality. Finally, with regard to relationality, interviewees lived end-of-life communication through their relationships with family caregivers and colleagues. The supportive role of colleagues was expressed as teamwork, which helped promote reflexivity about how to tailor communication, manage challenging emotions and situations, set aside time for communication, and prepare family caregivers for death.

Conclusion: End-of-life communication was an all-encompassing experience for nursing home staff. The supportive role of colleagues was stressed across all existentials, suggesting that teamwork is essential in delivering effective communication at the end-of-life.

Patient or Public Contribution: There was no patient or public contribution to this study, which addresses the experiences of nursing home staff only.

KEYWORDS: communication, end of life, hermeneutics, lifeworld existentials, nurse, nursing home, qualitative study

## **1 INTRODUCTION**

The literature provides several definitions of end-of-life communication in nursing homes (NHs), including (a) a "discussion" about life-sustaining treatments, care goals, advance directives, prognosis or the possibility to withdraw treatments or palliative care options; (b) "speaking" about symptom management or future care; (c) "talking" about how a resident is doing; or (d) "receiving information" about a resident's health problems or what to expect (Gonella, Basso, et al., 2019). Thorough end-of-life communication has been associated with better quality of care in NHs and has been identified as essential to promote effective person-centred care. High-quality end-of-life communication helps fulfil the physical, psychological, spiritual and existential needs of residents and family caregivers (FCs), and promotes trust and therapeutic alliance (Towsley et al., 2015).

Despite these well-recognized benefits, end-of-life communication in NHs is often poor, delayed or simply absent (Morin et al., 2016). Few NHs enact end-of-life communication systematically, and only a minority have written procedures on the involvement of residents or their FCs in care discussions, or on how to communicate during clinical deterioration or after death (Gonella, Clari, et al., 2021). Missed conversations tend to occur when neither NH staff nor FCs recognize that a resident's clinical condition is changing, or when either party assumes to know the resident's end-of-life care preferences (Auriemma et al., 2022; Towsley et al., 2015). Studies have shown missed opportunities for end-of-life communication with physicians, who are often viewed by FCs as "missing in action" (Shield et al., 2005,), and little inclusion of FCs in care plan meetings (Reinhardt et al., 2017).

End of life is complex and involves clinical, psychological, social, spiritual, legal and financial concerns. Therefore, proper end-of-life communication requires a multidisciplinary team with corresponding competencies (Anderson et al., 2019; Towsley et al., 2015). Moreover, as responsibilities can be divided by field, pressure on individuals is alleviated (van der Steen et al., 2014). As nurses are often the principle source of information for FCs in NHs, they also routinely coordinate end-of-life communication in multidisciplinary teams (Gonella, Di Giulio, et al., 2022). Indeed, satisfaction with nurse communication has been associated with higher satisfaction with end-of-life care (Liu et al., 2012) and less aggressive treatments in NHs (Gonella, Basso, et al., 2019). Moreover, transnational studies have assessed the effectiveness of training NH nurses to conduct meetings with and support FCs who are presented with difficult decisions about end-of-life care (Harding et al., 2022; Hartigan et al., 2019).

Although a number of studies have explored NH staff's experiences of end-of-life communication, none has employed qualitative methodologies based on a dynamic research process in which the researcher has an active role – such as interpretive phenomenology (IP) (Smith et al., 2009)—to provide a more comprehensive, in-depth understanding of the lived experience..

### 2 BACKGROUND

There is consensus that NH residents and their FCs would benefit more from comfort-oriented care aimed at improving the quality of remaining life than from curative-oriented care meant to prolong survival (van der Steen et al., 2014). End-of-life communication allows residents and their FCs to reflect on and share their care preferences with NH staff. This communication facilitates partnerships, promotes understanding, allows NH staff to organize the care plan, and simplifies transitions in care goals as NH residents' conditions worsen and death approaches (Anderson et al., 2019; Gonella, Campagna, et al., 2019). Indeed, most residents cannot make care decisions at the end of life, often causing NH staff to rely on FCs (Mitchell et al., 2012). In these situations, good end-of-life communication between FCs and NH staff is crucial, as it reduces FCs' decision-making burden when a relative's wishes are unknown (Fosse et al., 2014), counteracts NH staff's fears of leaving something undone, and avoids legal problems (Furman et al., 2007; Gonella, Basso, et al., 2021). However, end-of-life communication is not always practiced or is delayed until a resident's health deteriorates (Evenblij et al., 2019). This delay is often justified by fluctuating disease trajectories and a lack of predictive certainty, which add complexity to end-of-life care decisions (Evenblij et al., 2019; Firnhaber et al., 2020). However, the literature also highlights a wide array of staff-related barriers to end-of-life communication that may be anticipated and addressed, including lack of training and multidisciplinary collaboration, uncertainty about prognostication, time pressure, emotional discomfort, lack of confidence, feeling unprepared to initiate and sustain such conversations, and fear of a negative impact on residents (De Vleminck et al., 2014; Furman et al., 2007; Travers & Taylor, 2016; Young et al., 2017).

Understanding the experiences of end-of-life communication among NH staff is critical to better highlighting- and addressing-related challenges. In-depth exploration of these experiences may help identify personal, social, and professional needs, and underpin the development of context-specific strategies to help NH staff engage in these conversations. Moreover, this understanding may help identify difficulties in end-of-life communication that can be used to inform the design and implementation of appropriate services and interventions to improve this communication.

## **3 THE STUDY**

#### 3.1 Aim

This study aimed to explore and understand the lived experiences of end-of-life communication among NH staff.

#### 3.2 Design

This is an IP study based on van Manen's hermeneutic approach. IP was preferred because it aims to provide detailed examinations of a person's lived experience and gives an active, dynamic role to the researchers as they try to make sense of the interviewees, who in turn are trying to make sense of their own world. Moreover, IP is idiographic in its commitment to explore each interviewee's experiences deeply before moving towards more general claims (Smith et al., 2009). van Manen's approach is composed of four lifeworld existentials (i.e. lived space or spatiality, lived body or corporeality, lived time or temporality and lived human relations or relationality) and offers a heuristic guide for reflecting on the human experience without imposing predetermined themes (van Manen, 2015). This study is reported according to the COnsolidated criteria for REporting Qualitative research (COREQ) checklist (Tong et al., 2007) (Table S1).

## 3.3 Sample/participants

Forty-four NHs in different regions of Northwest Italy were purposively invited to the study to guarantee the greatest variation of data; six accepted to participate. Characteristics of participating NHs (e.g. public/private profile, number of beds, Alzheimer unit, staffing, written procedures on communicating clinical deterioration or bereavement management) have been published elsewhere (Gonella, Di Giulio, et

al., 2022). Managers from participating NHs were contacted by telephone and received the study protocol by email.

NH staff were eligible for inclusion if they (a) had a clinical role; (b) had been employed in the facility for at least 6 months; (c) had worked at least 10 shifts in the previous month; (d) communicated with FCs and (e) were willing to participate in the study. Using these criteria, NH managers identified 26 staff members and sent them a preliminary invitation. Twenty-one agreed to participate (Table 1) and their names were given to the research team, who verified that NH staff met all eligibility criteria and then contacted them by phone to arrange an interview. Recruitment continued until no new analytical information was noted. Of the six participating NHs, two contributed with five interviews each, one contributed four, one contributed three and two contributed two interviews each.

## 3.4 Data collection

A topic guide based on relevant literature (Anderson et al., 2019) and on the research team's experience in qualitative methodology and end-of-life care was developed and piloted among two NH staff. Only minor amendments were made following the pilot, and the pilot data were not added to the final dataset.

Using the amended topic guide, one researcher (AA) with no relationship to the NH or to interviewees conducted in-person, semi-structured, in-depth interviews from May 2021 to August 2021, while COVID-19-related restrictions were in place. Interviews took place in a quiet, private room of each NH, and interviewees could choose to have the interview before, at the end of or during their work shift. No one other than the interviewee and the researcher was present at the interview. Interviewees could choose the language of the interview, and all chose Italian as the language in which they felt most comfortable expressing their experiences. Only one interview was performed per interviewee, which is deemed sufficient for IP analysis (Smith et al., 2009).

Interview questions included: (a) What has been your experience with providing end-of-life communication in your NH and what does it mean to you?; (b) What has been your experience with starting end-of-life communication?; (c) What has been your experience with sustaining end-of-life communication? and (d) How have you experienced the relationships with FCs during and after end-of-life communication? The mean duration of interviews was 37 minutes (range 21–67). Audio recordings and field notes were maintained throughout the process.

## 3.5 Ethical considerations

The Ethics Committee of the University of Torino approved the study protocol (number 0598416/2021). All interviewees received oral and written information about study aim and data collection procedures and provided written informed consent to participate in the study and for their interview to be audio-recorded. Interviewees could stop the interview at any time and for any reason. Transcripts were anonymised for both the NH and the interviewee.

## 3.6 Data analysis

All audio recordings were transcribed verbatim into a Microsoft Word document alongside the corresponding field notes. One researcher (SG) randomly checked 10 transcripts for accuracy. Anonymised transcripts were exported to Atlas.ti version 8 for data management.

Data analysis involved the phases of data immersion, theoretical and open coding, creation of categories and thematic analysis. To ensure inter-rater agreement, two researchers (BA and SG) repeatedly read interview transcripts to get a full understanding (i.e. data immersion), did an independent analysis and finally met to share their coding sheets. Discrepancies were discussed, and a consensus list of codes was created. This consensus list was used by a third researcher (AC) to recode the full set of transcripts. Field notes were analysed concurrently with the interview transcripts to add more context to the interpretation of findings.

All researchers utilized the four existentials as a framework through which to begin data organization (i.e. theoretical coding), while simultaneously adopting open coding within each existential. All four existentials were explored simultaneously in each transcript. Statements reflecting interviewees' lived experiences of end-of-life communication were highlighted and their meanings were labelled. The same statements could be coded for more than one lifeworld existential since the existentials exist as interconnected facets of the single phenomenon "experiences of end-of-life communication" (Errasti-Ibarrondo et al., 2018). Once all data were coded, the same three researchers (BA, SG and AC) re-reviewed the data independently, to explore how the codes could be related to developing categories that connected the data logically and authentically. Once categories were created, the existentials were employed as guides for thematical reflection on the meaning of experiences of end-of-life communication by moving beyond descriptions of categories and offering explanation and interpretation (Errasti-Ibarrondo et al., 2018). Repetition of words or synonyms across existentials provided guidance to identify a single overarching category. Then the three researchers engaged in a final discussion to enhance analytical rigour and achieve consensus. These outcomes were then discussed within the research team, so that all researchers could provide feedback and reach consensus. Existentials are illustrated by significant quotes, identified by a code that indicates the staff member's profile and the NH (e.g. nurse/NH1, NH manager/NH2). Quotes deemed illustrative by the research team were translated into English (target language) for the purposes of publication, and backtranslated to ensure reliability in reporting. Two different team members (AC and SG) were engaged in the translation and back-translation processes for the purposes of rigour. Both translators understand not only the source and the target languages but also the two cultures (Chen & Boore, 2010).

### 3.7 Rigour

Guidelines for trustworthiness and authenticity were followed (Lincoln & Guba, 1986). Several strategies were employed to attain credibility and dependability. The semi-structured interviews enabled an in-depth understanding of NH staff's lived experiences of end-of-life communication and were conducted by a graduate nurse who received additional training in conducting qualitative interviews. Moreover, interviewees could review their interview transcript. Two researchers independently analysed transcripts and then met to consolidate codes, which were further validated by a third researcher. The research team kept an audit trail and adhered to hermeneutic alertness over the entire study. Triangulation within the team helped to identify categories and significant quotes and offer explanations and interpretations of findings. All these strategies ensured confirmability. Transferability was pursued by describing the data collection process and sample characteristics and seeking data saturation. Finally, authenticity was sought in an impartial way by considering viewpoints that were representative of multiple NH parties engaged in end-of-life communication.

#### **4 FINDINGS**

Overall, 13 categories that captured NH staff's experiences with end-of-life communication were identified and framed within van Manen's four existentials (van Manen, 2015). Communication, end of life, death and dying were recurrent words across all existentials, thus the overarching category "communicating at the end of life" was identified (Figure 1).

#### 4.1 Lived space (spatiality)

Lived space describes the place in which interviewees moved and found themselves during end-of-life communication. NH managers, nurses, occupational therapists and nurse aides mainly perceived this as a physical space, psychologists as a mental and socio-cultural space, and chief medical officers as a professional competence space.

#### 4.1.1 Physical space: Environmental obstacles and facilitators

Interviewees reported that bulky personal protective equipment (PPE) and pandemic-related visitation restrictions, which imposed limited body communication and lack of physical contact, were physical

obstacles to end-of-life communication. However, a familiar atmosphere, NH leadership that set communication among its priorities, and the physical presence of FCs in the facility were described as facilitators:

"I miss the physical contact with FCs, even just a hand on the shoulder to help them not feel alone. (Nurse aide/NH6)"

"The NH becomes a kind of home. Relationships [between staff and FCs] are much closer than in acute care settings, and this facilitates communication. (NH manager/NH6)"

"I can't stand this bulky equipment and physical distance. I used to rely on body language and physical contact when communicating with FCs (...) this is no longer possible. (Nurse/NH1)"

## 4.1.2 Mental space: Reflexivity

Staff were often unsure how to initiate end-of-life communication with FCs. Reflexivity in the form of selfreflection and team meetings helped staff identify the best way to approach sensitive topics. Interviewees commonly reported reflecting on experiences with end-of-life communication and related feelings alone and with colleagues:

"As a team, we always ask ourselves about the best way to start difficult conversations, and how to tailor them to each FC. (Psychologist/NH4)"

## 4.1.3 Socio-cultural space: Breaking the taboo

End-of-life was experienced as a taboo subject and had rarely been discussed in advance, so FCs usually did not know their relative's care preferences. Therefore, staff considered it essential to discuss end-of-life care options and preferences with FCs immediately upon their relative's admission to the NH. Such conversations became the responsibility of staff members who were judged most capable due to their educational background, like psychologists:

"Sometimes I feel like a vulture who has to start a taboo topic. When we realise that death is nearing, colleagues often tell me 'The floor is yours because you know how to say it.' (Psychologist/NH2)"

## 4.1.4 Professional competence space: Respecting limits

Interviewees reported the need to establish and respect the limits of their professional competencies during end-of-life communication. They also acknowledged the risk of exceeding these limits. Some learned from experience not to violate colleagues' field of competence and most referred FCs to appropriate colleagues when questions were outside their competence. Some interviewees perceived a hierarchy of competencies in communication, while others perceived that their role was minimized:

"Everyone should recognise their role and limits, and communicate within their area of competence. (...) physicians and nurses are responsible for discussing health-related issues, nurse aides can provide information about activities of daily living, while administrative staff is in charge of bureaucracy. (Chief medical officer/NH6)"

"I frequently hear that it is nurse aides who most often notice changes in health status, since they spend the most time with the residents. However, we can only mention changes we see to our superiors; we are not supposed to discuss them [with FCs]. For the most part, we are not allowed to contribute to end-of-life communication. (Nurse aide/NH5)"

## 4.2 Lived body (Corporeality)

Lived body describes how interviewees perceived their own bodies and emotions during end-of-life communication.

## 4.2.1 Acknowledging and managing challenging emotions and situations

Interviewees found end-of-life communication emotionally difficult and highlighted the need to acknowledge FCs' emotions to manage the communication adequately. FCs' emotions varied over the care period, from hostility to anger or suffering. Each experience was unique, influenced by the degree of FCs' awareness of their relative's deterioration, the uncertainty of the prognosis, and the personal situations of the NH staff themselves, such as a recent death in their own family. Interviewees often struggled to explore how well FCs understood their relative's condition, manage prognostic discordance and denial, and prepare FCs for their relative's death:

"I had several end-of-life communication experiences, and they have all been different. Communication changes based on who you have in front of you, and you need to adapt your manner and content accordingly. (Psychologist/NH6)"

"FCs often ask me, 'How much time is left?' I never know what to answer, because it is difficult to make accurate predictions. It might be 2 days or 2 months. (Nurse/NH1)"

Staff experienced strong emotions, and they found it helpful to discuss cases with colleagues to manage these emotions:

"Discussing cases with colleagues was an opportunity to reflect on and exchange challenging personal experiences. (NH5/nurse aide)"

The COVID-19 pandemic made remote end-of-life communication more common, but interviewees found it distressing. Remote communication was defined as limiting, incomplete, biased, sterile and unsatisfactory, with a high risk of misunderstanding. Interviewees felt that end-of-life communication requires in-person contact to be sensitive:

"Remote communication comes across as false and sterile. The medium carries news but no emotion. I give updates but with little idea of how the person is taking them (...). It makes it impossible to rely on body language to determine how much information the FC can handle. (NH manager/NH5)"

#### 4.3 Lived time (temporality)

Temporality refers to the passage of time in relation to experiences of end-of-life communication.

#### 4.3.1 Having the time to prepare family caregivers for their relative's death

NHs were perceived as places where there should be enough time to prepare FCs for their relative's death since death usually occurs after a medium to long stay. Cognitive, behavioural and emotional preparation for death required exploring FCs' acceptance of upcoming death and responding to any doubts that their relative's condition was worsening. Continuous communication and regular meetings between staff and FCs helped FCs understand what to expect:

"NHs are a place where people usually die after a long stay, so we should have time to prepare FCs. (NH manager/NH6)."

"Most cases degenerate slowly, and communication is a gradual journey. (Psychologist/NH4)"

#### 4.3.2 Finding the time to communicate

Communication was perceived as a priority, particularly end-of-life communication. Staff knew they were responsible for initiating communication with FCs about residents' clinical condition and for providing regular updates so as to avoid unpreparedness in case of a sudden downturn. Staff were cognisant of the importance of taking time to answer FCs' questions and of avoiding hurried responses that might leave FCs without a full understanding of the situation. However, setting aside time for communication was not easy; staff had to work together to create timetables that squeezed in family meetings among all their other care tasks:

"I had to establish a timetable for family meetings to provide FCs enough time to share their doubts. Family meetings had to be squeezed in somewhere, and we had to check with colleagues (...) to avoid overlap with their other activities. (Occupational therapist/NH5)"

## 4.3.3 Compensating for time constraints with time quality

Staff viewed end-of-life communication as part of their care tasks, but they complained that there was too little time for it, even when residents had longer stays, due to the low staff-to-resident ratio mandated by regional staffing regulations. Moreover, urgent and temporary relief NH admissions were becoming more common than traditional, long NH stays, leading to the postponement of communication until times of crisis. Staff tried to compensate for time constraints with high-quality interactions:

"We are really short of time. If we had more time, we could talk more with FCs, and care decisions would be made earlier. (Chief nurse/NH6)"

"Unfortunately, communication is often initiated only in times of (...) emergency. Moreover, regional staffing regulations allocate minutes of nursing care for certain categories of residents. However, we also have to provide nursing care to people who fall outside these categories. (NH manager/NH2)"

"Now, [end-of-life] communication often is done in times of crisis, because people move into NHs only when their conditions are already severely compromised. It is no longer a scheduled entry as it was in the past. (Chief nurse aide/NH2)"

"The essence of caring is not only the amount of time you provide, but also the quality of the time you offer. (NH manager/NH1)"

## 4.4 Lived human relations (relationality)

This existential describes the connectedness between staff and FCs, and among NH staff.

#### 4.4.1 Tailoring communication

Staff valued personalized, comprehensive, truthful, and empathic communication to establish relationships with FCs. Communication strategies varied according to the situation: silence, body language or even remote communication (e.g. long-distance FCs and urgent communication). Generally, interviewees considered it essential to use simple language and avoid medical jargon and technical terms; informal approaches and direct communication were not advised when strong, trusting relationships were not present:

"You don't always communicate in the same way; communication depends on the person you have in front of you. (Chief medical officer/NH2)"

"A hug, a hand on the arm, a smile, you can talk without using words. (Chief nurse/NH4)"

## 4.4.2 Tailoring support

Staff listened to FCs to understand their needs and tailor support accordingly. Some FCs wanted detailed clinical information, others needed guidance in making decisions, and others needed reassurance that their relative was not suffering. Finding the right words to support FCs was not easy:

"Some need to know little, others a lot; some want details, others just want a general overview; some need support and reassurance. Understanding which of these is needed to be truly supportive is hard. (Chief medical officer/NH2)"

## 4.4.3 Connectedness to family caregivers

Staff experienced communication as a mutual exchange which benefited and satisfied FCs. Connectedness was hindered when staff perceived FCs as pretentious, insistent, rude, or intrusive and in case of distrust or prognostic discordance. Trust was slow to develop and could be threatened by events like a confusing phone call, poorly informed staff members or alternative sources of information. Establishing

connectedness was harder and extremely stressful when families were fragmented and in conflict. COVID-19-related visitation restrictions also negatively affected connectedness. Even when FCs were allowed in the facility, PPE allowed for limited body communication and physical contact, which hindered relationships. Frequent, in-person meetings that started at admission, explaining each staff member's role to FCs, attention to body language, guidance in and making shared care decisions, and free access to the facility promoted connectedness. Caring attitudes such as availability, closeness, kindness, patience, presence and professionalism were also essential in developing connectedness with FCs:

"I have given and my reward has been the satisfaction of seeing FCs at peace. (Chief nurse aide/NH6)"

"Trust strengthens over time and leads to mutual esteem. As death approaches, everything is easier if good relationships have been established. (Nurse/NH3)"

"I have difficulties listening to FCs who want to do everything to prolong a relative's life. One son had us place a feeding tube for his mum, though she is cachectic, she is dying. This makes me angry. Then I give up and say, 'Do as he wants, even if I disagree.' (Chief nurse/NH6)"

"When you have to communicate with siblings who don't talk to each other or are at odds, it's awful, especially when important decisions need to be made. (NH manager/NH4)"

### 4.4.4 Experiencing an intermediary role

The staff experienced an intermediary role in communication between FCs and residents, and between FCs and hospital services. This intermediary role was expanded during the COVID-19 pandemic due to visitation restrictions which prevented FCs from accessing facilities and care services freely:

"We have always been a conduit, but this pandemic has made us more aware of this role. (NH manager /NH1)"

"I regularly offer FCs video-calls with their relative, because it's important to keep them in touch despite pandemic-related restrictions. (Occupational therapist/NH6)"

#### 4.4.5 Relying on colleagues

Colleagues were a precious source of support to manage difficult end-of-life communication and promote FCs' awareness about their relative's clinical situation and evolution of disease. Moreover, discussion and consensus within the team was essential to communicating a single, common message to FCs when residents deteriorated. Unfortunately, such discussions were not always possible due to limited time:

"FCs often don't accept the situation, so multidisciplinary meetings involving the general practitioner, palliative care physician, chief nurse, and the NH manager are arranged to promote awareness. These meetings are extremely useful because everyone has their role, and an effective communication balance is maintained. (Chief nurse/NH2)"

"All staff members meet periodically, discuss cases and establish a common response to FCs' questions. Once we determine this response, I am confident in rebutting FCs when they say, 'your colleague told me...' (Chief nurse/NH6)"

"We should have weekly team meetings to discuss difficult cases, but this is not always possible because there is not enough time. (Nurse aide/NH5)"

#### **5 DISCUSSION**

The dynamics of end-of-life communication vary across care settings and may affect how this communication is experienced. In acute care settings, physicians usually manage these conversations, while other social and health professionals offer emotional support and help FCs understand complex

information (Anderson et al., 2019). However, on-site physicians are rare in Italian NHs, making NH staff responsible for timely, honest, compassionate end-of-life communication (Gonella, Clari, et al., 2021). This study sought to explore and understand the lived experiences of end-of-life communication among NH staff by employing the lifeworld existentials of spatiality, corporeality, temporality and relationality as a reflective strategy.

## 5.1 Spatiality

End-of-life communication was experienced as a physical, mental, socio-cultural and professional competence space. End-of-life communication took place both in real and virtual settings. Interviewees experienced PPE and remote communication modalities as obstacles and highlighted the role of physical contact in supportive end-of-life communication. Sensitive physical contact helped demonstrate emotional closeness, belonging and attachment, which FCs have deemed essential to establishing relationships and providing person-centred care (Lopez et al., 2013). In agreement with a previous study (Gonella, Basso, et al., 2022), a familiar atmosphere was favoured by FCs' presence in the facility and promoted clear and thorough communication. NH staff also experienced end-of-life communication as a mental space in the form of reflexivity on an individual and team level. Similar to previous results (Olson et al., 2021), reflexivity in the form of self-reflection and team meetings fostered continual language adjustment that was also influenced by staff's personal feelings. Multidisciplinary team meetings played an important role in deciding how to interact with FCs and in promoting tailored, person-centred communication that addresses sensitive issues, which is a core element of palliative care delivery at the end of life (van der Steen et al., 2014).

This suggests that NHs must create an open environment in which staff, residents and FCs feel safe and comfortable sharing their feeling and thoughts. Indeed, FCs have reported that they experienced higherquality communication and felt more involved in care planning when a team-based approach to end-of-life communication was employed (Frey et al., 2020). NH staff experienced end-of-life communication as a socio-cultural space, in which both staff and FCs felt some resistance to frank communication about death. End-of-life communication was a "hot potato" that was passed within the care team, as FCs were often unaware of their relative's end-of-life care preferences (Gonella et al., 2020), and not all staff felt prepared to sustain such a discussion (Harrison Dening, 2016). Our findings confirm the need to continue to break the taboo surrounding death and dying (Thulesius et al., 2013), particularly in majority-Catholic countries such as Italy, where the model of maintaining FCs' hope often results in missed or delayed communication (Toscani & Farsides, 2006). Breaking this taboo and providing transparent, timely, thorough communication could help FCs better accept the transition from curative-oriented to palliative-oriented care (Gonella, Basso, et al., 2022).

Finally, NH staff experienced communication as a professional competence space, in which their professional profiles had an influence. As in previous studies (Anderson et al., 2019), our interviewees recognized the need to respect the limits of their professional competencies when conducting end-of-life communication. Nurses reported mainly physical nuances during end-of-life communication. However, nursing education emphasizes self-reflection and caring for a person as a whole as pillars of nursing practice. As such, nurses may take these aspects for granted and thus not report them (Coffey et al., 2019). It is also possible that chronic understaffing, compounded by the pandemic, forced NH nurses to focus on more practical issues when communicating (Campagna et al., 2021). This issue deserves further investigation.

## 5.2 Corporeality

As in earlier reports (Olson et al., 2021), staff acknowledged challenges in managing their own emotions and those of FCs during end-of-life communication. End-of-life communication was particularly demanding for NH nurses, who often represent FCs' main point of contact for discussing prognosis. Indeed, prognostication is complex in the elderly, which can increase the emotional burden of end-of-life communication (Yourman et al., 2012). Training and resources on how to conduct conversations about

serious illness could be integrated into the curriculum and continuing education of healthcare professionals to increase their confidence in end-of-life communication (Buckman, 2017). Interprofessional training regarding diagnosis and prognosis-related communication is also essential to promote collaboration and to better empower nurses in this practice. Finally, having the flexibility to respond to different situations and individuals, and to discuss with colleagues in structured, peer-facilitated informal groups may allow healthcare professionals to normalize their emotions and learn coping strategies (Borghi et al., 2021). Our findings suggest that healthcare professionals should be provided emotional support, social support and communication training in an environment that allows time for reflective practice.

### 5.3 Temporality

Interviewees perceived NHs as privileged places for end-of-life communication. Indeed, NH residents usually have longer stays, which should leave time for multiple conversations that introduce and reinforce information, facilitate FCs' gradual acceptance and understanding, and prepare them for death and bereavement (Hebert et al., 2009). However, despite the recognized benefit of early end-of-life communication, about one-third of conversations occur within 1 month of death (Reinke et al., 2017). In our study, NH staff ascribed delays in communication to staffing issues and increases in urgent and temporary relief admissions. Interviewees perceived communication as a priority and made great collective efforts to schedule time for this activity without compromising other care tasks. To compensate for the lack of time, staff tried to engage in high-quality interactions with FCs.

### 5.4 Relationality

End-of-life communication experiences usually included FCs and colleagues, not residents. This confirms the tendency to postpone such communication until recovery is impossible and residents have lost cognitive capacity (Gonella, Basso, et al., 2019). Interviewees reported that tailoring communication and support to the situation and to each FC's individual needs favoured connectedness and had mutual benefits. Our findings confirmed well-known barriers to (distrust and prognostic discordance) and facilitators of (clarifying each staff member's role, staff members' caring attitudes and frequent, in-person meetings) end-of-life communication (De Vleminck et al., 2014; Travers & Taylor, 2016). Our interviewees also experienced relationality as an intermediary role between FCs and their relatives, and between FCs and hospital services. The role of intermediaries in improving the quality of care, particularly at the end of life, has been already highlighted (MacDonald et al., 2011). Our findings suggest that restrictions strengthen the intermediary role of NH staff. For example, restrictions aimed at containing the spread of COVID-19 expanded the role of NH staff in ensuring timely communication with FCs (Hado & Friss Feinberg, 2020). Finally, NH staff's lived experiences of end-of-life communication was one of teamwork: they sought and relied on colleagues' support to manage difficult conversations with FCs, to promote FCs' understanding of their relative's prognosis, and to handle mismatched expectations. These findings confirmed that teamwork is essential to providing end-of-life communication according to palliative care guidelines, which recommend multidisciplinary teamwork to ensure person-centred communication and high-quality care (van der Steen et al., 2014).

Our findings may serve to guide healthcare policymakers who wish to invest in communication skills training that focuses on conversations about serious illness and may guide the planning and structure of such training. Finally, our findings highlight the need to make psycho-social, supportive services available to healthcare professionals to safeguard their well-being, due to the emotionally demanding nature of end-of-life communication.

#### **5.5 Limitations**

This study was conducted during the COVID-19 pandemic, which may have emphasized some nuances of end-of-life communication experiences, such as challenges in establishing trusting relationships and managing emotions due to limited in-person communication, increased staff shortages and turnover as extra nurses were called into hospitals. However, we believe that our findings apply beyond the COVID-19 timeframe, as the challenges highlighted are well-known in the end-of-life literature. Moreover, it is

possible that the data analysis we adopted (i.e. exploring all four lifeworld existentials simultaneously in each transcript) privileged the existential of relationality over the others since end-of-life communication is a sensitive phenomenon that is influenced by relationships among parties. The existential of lived human relations was indeed the most grounded. A different analytical approach, such exploring each lifeworld existential consecutively in all transcripts, may have provided different results (Rich et al., 2013). However, during the theoretical coding process, the use of lifeworld existentials should have amplified each existential equally across the interviews. In addition, "a phenomenological description is always 'one' interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description" (van Manen, 2015). Finally, this study was performed in the Italian long-term sector. Because this sector is managed on the regional level, staff-to-resident ratios and the organization of internal processes vary largely by region. None of our NHs had in-house physicians to whom FCs could turn for information at the end of their relative's life, and high staff turnover also had an adverse effect on communication experiences. This study characteristic may limit the transferability of our findings to other jurisdictions and health systems.

## **6 CONCLUSION**

End-of-life communication was an all-encompassing experience for NH staff, with spatiality, corporeality, temporality, and relationality features. A highlight of the study was the central role of teamwork in communicating at the end of life, as suggested by the ubiquity of this concept across all lifeworld existentials. Discussion during team meetings promoted reflexivity about the best way to tailor communication to individuals and situations (spatiality), helped manage challenging emotions and situations (corporeality), helped plan time for communication (temporality), and promoted FCs' awareness about disease progression based on a shared plan (relationality).

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## TABLE 1. Interviewees' characteristics

Healthcare professionals (n = 21)	Ν
Female gender	17
Age, years, mean [range]	50 [25–73]
Education	
High school diploma	2
Bachelor's degree	10
Master's degree	9
Professional profile	
Nursing home manager	4
Chief nurse	4
Chief medical officer	3
Nurse	3
Psychologist	3
Occupational therapist	2
Chief nurse aide	1
Nurse aide	1
Overall working experience, years, mean [range]	16 [1–50]
Working experience in nursing home, years, mean [range]	8.5 [0.5–25]
Employment	
Permanent full-time	14
Freelance	6
Permanent part-time	1

#### **FIGURE 1**

Lived body Acknowledging and managing challenging emotions and situations

#### Lived time

Having the time to prepare family caregivers for their relative's death Finding the time to communicate Compensating for time constraints with time quality

Communicating at the end of life Lived human relations Tailoring communication Tailoring support Connectedness to family caregivers Experiencing an intermediary role Relying on colleagues

## Lived space

Environmental obstacles and facilitators Reflexivity Breaking the taboo Respecting limits